

REPORT TO THE CONGRESS
on
POLICIES FOR IMPROVING SERVICES FOR
MENTALLY RETARDED AND OTHER
DEVELOPMENTALLY DISABLED PERSONS
SERVED UNDER TITLE XIX OF THE
SOCIAL SECURITY ACT



Submitted by
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FOREWORD

The Department of Health and Human Services supports the goals of independence, productivity and integration into the community of mentally retarded and other developmentally disabled citizens. We welcome the opportunity in this report to Congress to review our progress toward these goals and to outline four policy proposals which we believe will advance us even further.

The Intermediate Care Facilities for Mentally Retarded (ICF/MR) program was established by Congress under Medicaid nearly 15 years ago as a mechanism to provide care to a severely handicapped population. In 1973, the program's first year of operation, 30,500 individuals received ICF/MR services at a cost of \$165 million. By 1983, Medicaid paid just over \$4 billion for 151,000 people. During this same time period, the number of large institutions decreased and more clients were served in smaller community-based facilities. The average age of clients in ICFs/MR increased as more families chose to care for their developmentally disabled member at home.

More recently, Section 2176 of the Omnibus Reconciliation Act of 1981 authorized the granting of waivers of certain Medicaid requirements to allow States to cover home and community-based long-term care services under Medicaid. As of June 30, 1985, 107 waivers have been granted to 46 States. Fifty of the approved waivers are targeted to developmentally disabled people.

The Department has identified four areas for emphasis. They are: increased incentives for community living, improved standards for ICFs/MR, adult services and improved coordination and cooperation. The report outlines plans in each of these areas.

We are committed to moving forward and believe that by 1992, the close of the Decade of Disabled Persons, we can reach the goals set forward in the Developmental Disabilities Act of 1984.



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Secretary

POLICIES FOR IMPROVING SERVICES
FOR MENTALLY RETARDED AND DEVELOPMENTALLY DISABLED PERSONS
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ACT

SUMMARY

The Developmental Disabilities Act of 1984 requires that the Secretary of Health and Human Services submit to Congress a report on services provided to developmentally disabled and mentally retarded persons under the Medicaid program, including the home and community based service option. The report is to focus on improving services in such a manner as to increase the independence, productivity and integration into the community of mentally retarded and other developmentally disabled persons.

The Department of Health and Human Services is firmly committed to the goals of independence, productivity and integration into the community of mentally retarded and other developmentally disabled people. Considerable progress has been made toward achieving these goals and the Department will continue efforts to assist States in providing opportunities for all individuals, including those who are most severely handicapped, to live in an environment which is similar to that of the majority of society and one which enables them to achieve their maximum potential.

To this end, the Department is undertaking four efforts. The first is an examination of options which would allow States greater flexibility in providing services to mentally retarded and other developmentally disabled people.

Second, the Department is proposing revisions to the standards governing the Intermediate Care Facilities for the Mentally Retarded (ICF/MR) program. The revised regulations will continue to protect the health, safety and rights of vulnerable disabled persons. They aim to make standards more enforceable. Equally important, they also are being designed to increase the focus on developing the full potential of the individual through active treatment. Moreover, both the added flexibility and the revised regulations will facilitate the current movement to community-based services and encourage the integration of developmentally disabled people into the mainstream of society.

Third, the Department believes it is important to assist mentally retarded and other developmentally disabled people to become independent and productive. Therefore the

Department along with other Federal agencies will place special emphasis on focusing an array of services provided by Federal, State and local governments to facilitate the transition of young adults from school to work.

Finally, the Department of Health and Human Services will work to improve Federal agency cooperation and coordination, principally through the Interagency Committee on Developmental Disabilities. This Committee, called for in the Developmental Disabilities Act of 1984, is co-chaired by the Commissioner of the Administration on Developmental Disabilities, Department of Health and Human Services, and the Assistant Secretary of Special Education and Rehabilitative Services, Department of Education.

More than 20 years ago various programs of the Federal government became available to support the move from institutional to community-based care. This philosophical change in treatment and care necessitated a new set of services for a more independent life style. Today, 8 out of 10 mentally retarded children reside with natural or foster parents, and an increasing number of disabled adults are living outside institutional settings. The Department of Health and Human Services provides financial assistance through the Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), Medicaid and Medicare programs. These programs constitute the most significant Federal disability-related expenditures. The Department also funds programs which provide family services such as respite care, case management, counseling services and parent training. Most recently the Home and Community-Based Care waiver program, under Medicaid, provided States with further opportunities to meet the needs of severely disabled people in the community, thus delaying or preventing the need for institutional care.

The goal of the Administration is to foster the continuing development of strategies emphasizing integration into the community, independence and employment, while still providing support and protection for those persons who need such assistance.

BACKGROUND 1.

Changing Focus and Federal Legislation

Many changes in treatment of mentally retarded and other developmentally disabled people have occurred over the past two decades. The principle of "normalization" which underlies many of these changes argues that even the most - severely handicapped persons should be treated as much as

possible like other people of the same age and background. It stresses the importance of allowing people with all types of handicaps to have the same opportunities to engage in what are usually considered normal activities and lifestyles. Advocates of normalization believe individuals will reach their maximum level of independence and productivity only if their living and working environments are similar to those of the rest of the population.

The sixties and seventies witnessed a significant increase in legislation attempting to address the needs and concerns of disabled persons. Some of the most important pieces of Federal legislation enacted during this period were (1) The Architectural Barriers Act of 1968 which mandated physical access, paving the way for legislation dealing with civil rights and employment; (2) The Rehabilitation Act of 1973, particularly Section 504, which prohibits discrimination on the basis of handicap in Federally assisted programs; (3) The Education for All Handicapped Children Act of 1975 which requires that handicapped children be educated in the "least restrictive" environment; and (4) The Developmental Disabilities Assistance and Bill of Rights Act of 1975 which includes a protection and advocacy system, strengthened assurances regarding the rights of developmentally disabled people in institutions, and a State grant program.

2. Medicaid

The ICF/MR program, and the Home and Community Based Care program now available on a waiver only basis, are the two major components of the Medicaid program which States have used to target services to the needs of the developmentally disabled.

Medicaid, enacted as part of the Social Security Amendments of 1965, is a joint Federal and State financially supported, State administered entitlement program which pays for the health care of specific categories of low income people. Approximately 55 percent of the funds are Federal. Within Federal parameters, States now have considerable latitude to decide what groups to cover and for what types and amounts of services. All 50 States and the District of Columbia (as well as Puerto Rico, Guam, the Virgin Islands, Northern Marianas and American Samoa) currently have Medicaid programs. These differ in terms of groups of recipients served, types of services covered, and costs.

The eligibility provisions for the Medicaid program are complex and vary across the States. At a minimum, States

must provide Medicaid benefits to all persons receiving cash assistance under the Aid to Families with Dependent Children (AFDC) program. Generally, States must provide Medicaid

eligibility for recipients of benefits under the Supplemental Security (SSI) program, although States also have the option under Section 1902(f) of the Social Security Act to limit Medicaid coverage to SSI recipients who meet more restrictive Medicaid eligibility requirements. The persons eligible for Medicaid under these provisions are referred to as "categorically needy."

Also, there are optional categorically needy coverage groups associated with AFDC and SSI. Both programs include groups who: 1) are eligible for but not receiving cash assistance, and 2) would be eligible for cash assistance if not institutionalized.

AFDC has additional optional coverage groups who: 1) would be eligible if child care costs were paid from earnings, 2) are under 21 years of age and who would be eligible for AFDC but do not qualify as dependent children, and 3) would be eligible if coverage under the State's AFDC plan were as broad as allowed. SSI has additional optional coverage groups who: 1) receive only optional State supplements, 2) would be eligible under a special income level over the SSI level and are in institutions, and 3) would be eligible under a special income level over the SSI level and are receiving home and community-based services.

Most children who permanently reside in institutions qualify for Medicaid regardless of family income. In these cases, the income of the parents is not considered to be available for the child's care unless the parents actually contribute to the costs of care. Children with high medical costs, who are eligible for Medicaid while they are institutionalized, may lose their eligibility when they return home to live with their parents. States have two ways to remedy this: first, under Section 13 of P.L. 97-248, States are permitted to cover under Medicaid certain disabled children 18 or under who live at home and would be eligible for SSI if they were institutionalized. States must determine that the child would have required institutional care and that the cost of care at home is no more expensive. Second, States may apply for a Home and Community-Based care waiver to provide Medicaid services to disabled children with high medical costs who live at home.

In addition, States may provide Medicaid coverage to medically needy individuals. These include pregnant women, children, aged, blind or disabled individuals whose income is above the level established for the categorically needy. States set the income eligibility levels for medically needy individuals, but those levels may not exceed 133.3 percent of the State's AFDC income standard. If people defined as

medically needy have income or assets above the State-prescribed standard, they must first incur sufficient medical expenses to lower their income and assets to the medically needy level. This is often referred to as the "spend down" requirement.

Finally, individuals in States that do not have a medically needy program or spend down provision may receive Medicaid benefits if they reside in an ICF, ICF/MR or Skilled Nursing Facility (SNF) even if their incomes are too high to qualify them for cash assistance. These individuals may qualify if their incomes are below a State-defined level which must not exceed 300 percent of the SSI standard for an individual living in his or her own home.

Mentally retarded and other developmentally disabled people who are Medicaid eligible are also entitled to receive all other Medicaid services covered in their State plan. These could include physician services, clinical services and hospital services.

ICF/MR Program

Forty-nine States and the District of Columbia administer an ICF/MR program: 20 States for the categorically eligible and 29 States and the District of Columbia for both the categorically eligible and medically needy. Funding of care in intermediate care facilities (ICFs), including public facilities for the mentally retarded was added as an optional Medicaid service in 1971. The intent of the Federal funding and standard setting was to improve the quality of institutional care provided to the mentally retarded; too often this was little more than custodial care. Also there was a growing awareness that States had responded to the availability of Federal funding for skilled nursing facilities (SNFs) by reclassifying some State institutions or by moving mentally retarded residents from State institutions into private SNFs. Because of their intense, medical orientation, SNF services did not meet the habilitative needs of this population; this level of care was also very costly.

Although the evolution of the Medicaid ICF/MR program coincided with the development of normalization as a philosophy and treatment, normalization was not a part of its original mission. At the inception of this program, most observers assumed that Medicaid would continue to focus on large, but upgraded, public institutions.

In 1973, the first year of the ICF/MR program's operation, Medicaid paid \$165 million in Federal and State funds for 30,500 recipients of ICF/MR services. By 1983, the combined Federal and State share totaled just over \$4 billion for

151,000 ICF/MR recipients. (See Chart I) Initial growth in recipients, costs, and cost per recipient occurred as States certified already existing beds as ICF/MR beds. To do this, States invested heavily in capital and staffing improvements to bring these facilities up to Medicaid standards. During this time period, the total number of people being cared for in large public institutions was declining although an increasing proportion of these people was being cared for in Medicaid-certified facilities. Growing investments in staff, capital to improve facilities, costs of larger facilities as well as general and medical inflation can be contrasted with the overall declining residential population. In the mid-seventies, there was substantial growth in Federal and State expenditures for the ICF/MR program, although the rate of growth has leveled off.

Trends within the ICF/MR community are actually reflections of changes taking place within the total residential care system. State residential systems have decreased slightly in size, largely through increased movement toward semi-independent placements and delayed age of first entry into the long-term care system. A study by the University of Minnesota, for the years 1977 to 1982, substantiates similar trends in the ICFs/MR.

During the years 1977-1982, substantial growth occurred in the ICF/MR program, more in the number of facilities funded than in the number of certified beds. This increase in the number of facilities resulted in a decrease in the average number of beds per facility from 186 to 76. (See Chart II) The average size of large facilities (over 200 beds) has declined over the last 10 years. In 1981, public institution data showed the average size of large institutions fell from 700 beds to 475 beds. The greatest change in facility growth was in smaller facilities serving 15 or fewer clients. The number of small facilities grew from 188 in 1977 to 1,202 in 1982. (See Table A).

A related change during the five-year period was the growth in private facilities which increased from 573 in 1977 to 1,834 in 1982. The number of for-profit providers rose from 169 to 406. During the same time period, the number of non-profit facilities increased from 135 to 977. Despite the growth in the number of small private facilities, the ICF/MR program remains essentially public. Seventy-five percent of ICF/MR beneficiaries were residing in publicly operated facilities of 76 or more residents as of June 1982.

There has been a dramatic decrease in the proportion of children and youth among the resident populations served by ICFs/MR. In 1977 persons under 22 years made up 35.6 percent

of the ICF/MR population; in 1982, that proportion had dropped to 22.6 percent, a much faster decline than in the general population. (See Chart III)

There also has been a significant increase in the proportion of persons who are profoundly retarded in ICFs/MR. In the small ICF/MR serving 15 or fewer clients the levels of mildly to moderately retarded fell from 70 percent to 56 percent while the profoundly retarded increased from 3 percent to 16 percent between 1977 and 1982. In those ICFs/MR serving 16-75 residents, the mild to moderate population fell from 52.2 percent to 43 percent while profoundly retarded rose from 20.0 percent to 29 percent. In the 76-300 and 300+ facilities the decrease in mild/moderate was 39-32 percent and 24.5-18 percent respectively, with the profoundly retarded group increasing from 33-41 percent, and 47-58 percent respectively.

Eighty percent of the populations of large ICFs/MR and about 30 percent of clients in community settings are severely or profoundly retarded. The average age of clients in ICFs/MR is now well over 30 years reflecting the effect of other • programs enabling family members to retain their handicapped child/sibling in the home, efforts to serve disabled people in the least restrictive setting and efforts to limit institutional care to those who need it most.

Counts of the number of ICF/MR facilities and the number of certified beds in those facilities suggest a stabilization and even a small decrease in the number of ICF/MR program beneficiaries. In 1982, there were 148,393 ICF/MR beds in 1,853 ICF/MR facilities nationwide. This compares with 146,630 certified beds in 2,674 facilities in 1985. The decrease in the total number of certified beds is largely a result of closing large institutions or units in them. The increased number of facilities comes primarily from the growth of small facilities.

The States are responsible for ensuring that ICFs/MR meet program standards. In 1980, P.L. 96-499 authorized the Secretary of Health and Human Services to conduct "look behind" surveys. In order to establish whether a facility is in compliance and meets the requirements for participation in the Medicaid program, the Health Care Financing Administration conducts onsite surveys of facilities. If a facility is found not in compliance with health and safety requirements, the Secretary has the right to cancel that facility's approval to participate in the Medicaid program.

Since 1980, HCFA has issued "look behind" procedures and has required its Regional Offices to conduct surveys of at least five percent of certified ICFs/MR. Fifty-seven full-time

equivalent positions have been designated to conduct "look behinds" in ICFs/MR. Each Regional Office has at least one developmental disabilities specialist designated to participate in this effort.

The Department is committed to survey 100 percent of the ICFs/MR with 300 or more beds. In addition, HCFA will survey 40 percent of certified ICFs/MR with between 16 and 299 beds and 20 percent of ICFs/MR with 15 or fewer beds. To reach these goals, HCFA will conduct more than 650 direct Federal surveys on an annual basis.

An update on conditions at nine ICFs/MR is appended. These nine facilities were the focus of the Secretary's testimony before the Senate Labor and Human Resources Subcommittee on the Handicapped in July 1984. (Appendix A)

Home and Community-Based Care Waivers

Section 2176 of the Omnibus Reconciliation Act of 1981 authorized the granting of waivers of certain Medicaid requirements to allow States to cover home and community-based long-term care services under Medicaid. States can provide a wide array of non-medical services not otherwise covered by Medicaid to selected populations who might otherwise require institutionalization. To meet Federal requirements for waiver approval, States must demonstrate that Medicaid services provided including the new services are no more expensive than caring for those individuals in an institutional setting.

As of June 30, 1985, 107 waivers had been granted to 46 States. Fifty of the approved waivers were targeted to developmentally disabled people. The most frequently requested waiver services are case management, followed by habilitation, miscellaneous and respite. While most waiver requests are to provide services for mentally retarded people, some States have targeted other developmentally disabled persons as well.

The final regulations for the Home and Community waivers issued on March 13, 1985, include several new provisions which will help improve services to mentally retarded and other developmentally disabled people. The regulations now require board and care facilities in which home and community-based services are provided to meet applicable State standards as well as standards established under section 1616(e) of the Social Security Act, commonly referred to as the Keys amendment. This provision requires States to establish and enforce safety and related standards for institutions, foster homes, or group living arrangements where a significant number of SSI recipients are residing or

are likely to reside. Developmentally disabled people live in a variety of settings, including the kinds of facilities covered under the Keys amendment. The Department will impose the Keys amendment requirements on all facilities subject to the Keys amendment standards in which residents are receiving services through the Home and Community waivers.

The regulations also contain language to make clearer that a recipient must be given a choice of either institutional care or waiver services and now specify that the recipient or their legal representative must be involved in making this choice.

The waivers have assisted in the movement towards community-based care. Funds for community-based services for the mentally retarded and other developmentally disabled people increased between 1977 and 1984. For ICFs/MR, the proportion of funding for community-based settings (e.g. small group facilities located in residential areas) more than doubled and is estimated to be approaching 21 percent of the total Federal ICF/MR reimbursement in 1984 according to a study by the University of Illinois at Chicago. Moreover, the proportion of total funds, including both State and Federal monies, used for community-based services has increased in all States, with 10 States reaching fiscal parity in funding expended on community services and institutional care.

3. Other Programs

Mentally retarded and other developmentally disabled people are being served by a number of programs. These range from infant stimulation programs, through education and training provided by local school systems, to various adult programs in addition to residential services. Families receive services as well. These can include respite care, family support groups and estate planning to ensure lifetime care for the developmentally disabled family member. Federal sources of support include the Developmental Disabilities program, the Maternal and Child Health program, the Social Services Block Grant, Vocational Rehabilitation and Special Education.

The multitude of programs and activities for providing services to mentally retarded and other developmentally disabled people often creates problems as well as new opportunities. Critics point to the lack of coordination among Federal, State and local programs which can result in gaps in coverage. This difficulty has been noted by the HHS Inspector General in "A Program Inspection on the Transition of Developmentally Disabled Young Adults from School to Adult Services." The variety of programs available can make professional treatment and placement decisions more difficult.

DEPARTMENTAL GOALS

1. The Challenge

Proposals for improving the system include sometimes contradictory goals. For example, increased program integration can limit program flexibility. The goal of fewer Federal restrictions may conflict with the desire for stronger Federal standards. Specific proposals for improvement include higher quality treatment, more active treatment, greater support for families with mentally retarded members, movement of emphasis from institutional to community-based settings, and/or movement from sheltered work settings to mainstream employment including supported work. The challenge is to reconcile the goals of flexibility and accountability, and to fashion programs and practices which allow sufficient flexibility for meeting individual needs, while ensuring protection for the most vulnerable.

2. Goals

The Department is pursuing several major goals which it believes can contribute to the independence, integration and productivity of mentally retarded and other developmentally disabled people:

Goal: Increasing Incentives for Community Living

Despite the trend to smaller facilities, a common criticism of the current ICF/MR program is that it creates incentives for States to retain institutional models of care. Most large State institutions are ICF/MR funded while most small, community-based residential care facilities rely on a mix of Federal, State and local funds. While there is a trend to smaller ICFs/MR, a number of States have considerable capital invested in larger institutions. This and pressures to maintain jobs for staff have tended to slow the movement of clients out of larger facilities. In order to reduce incentives to States to maintain larger facilities, some have argued for the transfer of Federal Medicaid dollars from institutions to community programs. Others, however, believe that institutional care is more stable than community-based services, ensuring a lifetime of care. Others argue that institutions are necessary to provide care to the most severely handicapped and the medically fragile.

One way to achieve a better balance is to give States more flexibility in a manner which does not provide inappropriate fiscal incentives.

Goal: Improving Standards for ICFs/MR

Revised and updated standards for ICF/MR care and services are needed. The current ICF/MR regulations are outdated; they were published in January, 1974. At that time, most institutions for

the mentally retarded were large, State-run facilities. In 1981, HCFA issued guidelines for facilities serving 15 or fewer persons.

The current regulations and guidelines require "active treatment," i.e., an individualized written plan of care that sets forth measurable goals and objectives in terms of desirable behavior and prescribes an integrated program of activities, experience, or therapies necessary for the individual to reach those goals and objectives. This requirement was intended to prevent warehousing of clients and to promote maximum development.

Because the ICF/MR program is a component of the medically-oriented Medicaid program it has had a medical bias. While some ICF/MR clients have heavy medical needs, this is not the case for the majority. It has been argued that some of the requirements imposed on ICFs/MR, while appropriate to facilities serving the long-term physically disabled, may add significant unnecessary cost.

There is also evidence that some individuals in ICFs/MR do not have the level of disability warranting ICF/MR care. Inappropriate placement has been a continuing concern. The ICF/MR standards should be designed to avoid institutionalization of those not needing such a restrictive setting and should focus better on meeting the needs of those who do require such care.

Goal: Meeting the Needs of Adults

Several developments point to the need for an examination adult services. First, there has been a significant increase in the proportion of adults in ICFs/MR. Second, there is increased interest in the needs of young adults. As a result of the implementation of P.L. 94-142, The Education for All Handicapped Children Act of 1975, more mentally retarded students have been provided services in the public school system. Once these individuals reach the maximum age for school services, they are said to be "aging out." The schools have no formal responsibility for developing a program of services for a student after he or she leaves school. Young adults and their families often face a service delivery system that is uncoordinated and diffuse.

In sum, there is a growing concern about the availability of adult services as well as an awareness that work in as normal a setting as possible is preferable to a more controlled and protective environment.

Goal: Improving Coordination and Cooperation

Clearly, assisting the mentally retarded and developmentally disabled population to become more, integrated into the mainstream of American society, and to be less dependent on institutional

care, requires coordinated action by Federal, State and local agencies, the private sector, and families of this population. In particular, special efforts are required by agencies concerned with employment and education, and the interface between school and work.

Two new provisions in the Developmental Disabilities Act of 1984 encourage greater coordination at the State level. The Act requires that each State council must include in its membership the State agency which administers Medicaid funds. In addition, the Act requires State councils and protection and advocacy systems be provided copies of annual survey reports and plans of corrections in ICFs/MR.

POLICY PROPOSALS

In an effort to address these goals, the Department has undertaken a four part policy. This policy, formed within budgetary restraints:

- o increases flexibility for States to provide those services which are most needed to promote independence and integration;
- o revises the standards established for the ICF/MR program with particular attention given to those elements which inhibit small facilities and to the provision of active treatment to clients;
- o focuses on development of adult services; and o improves

Federal coordination. 1. Options to Encourage Community-Based Services and Contain Cost

The Department will be examining options which reduce incentives toward inappropriate institutionalization. These options should provide States with greater flexibility to provide a continuum of services while establishing workable cost controls. States would have increased flexibility in the allocation of funds to meet recipient needs including medical, social and rehabilitation services. In addition, the Department will identify methods to reduce existing fragmentation in planning, financing and service delivery for the mentally retarded and otherwise developmentally disabled population.

Any discussion of options must address the following:

- o achieving a balance between State flexibility and Federal requirements;

- o increasing the States¹ ability to provide care in the least restrictive setting appropriate to individual need;
- o providing an array of care options with an emphasis on home and community-based care;
- o protecting the health and safety of program participants;
- o tailoring services based on the needs and characteristics of the clients;
- o integrating a continuum of services such as habilitation, vocational, education and supported employment;
- o emphasizing vocational needs and potential, with employment a goal wherever possible;
- o establishing cost controls and administrative accountability; and
- o simplifying program administration.

The Department is already moving in this direction. A bill, introduced as S. 1550, would substantially increase State flexibility to more effectively target Medicaid resources to eligible groups. In essence, this proposal, subject to the enactment of a Medicaid cap, establishes a core program for the mandatory categorically needy. The core program consists of a minimum package of services which must be provided to all categorically eligible persons in a comparable manner throughout the State. Beyond this, however, States would have complete flexibility to decide which Medicaid services to provide to the optional categorically needy and the medically needy. Therefore, States would be able to tailor benefits to different eligibility groups, based on their individual needs and characteristics, without having to provide the full package of services to covered groups on a state-wide basis. The Department believes this proposal could result in improved services to the developmentally disabled.

Future recommendations for financing services to this population could include the establishment of a separate funding mechanism for the developmentally disabled. Such a program would be closed-ended at the Federal level and could incorporate opportunities for exploration by the States of alternative services arrangements. Issues to be addressed in this type of approach include the identification of existing Federal funds to fold into such a program, allocation of funds among the States, determination of the States' financing role, and administration at both the Federal and State levels.

2. Improved ICF/MR Standards

The Department will propose a general revision of the regulations establishing standards for the ICFs/MR. These standards are the requirements that ICFs/MR must meet if they are to participate in the Medicaid program. The revisions are being designed to increase the focus on the provision of active treatment services to clients, to clarify Federal requirements to maintain essential client protections, and to provide State survey agencies with a more accurate mechanism for assessing quality of care. The revisions will change requirements to take into account the decrease in the average size of institutions, litigation, legislation, research, and technological advances that have changed attitudes and influenced the way clients are identified, assessed and provided services.

In developing these standards, the Department is emphasizing the client and client outcomes while reducing unnecessary paper requirements. The standards will be based on accreditation standards published in 1983 by the Accreditation Council for Services to Mentally Retarded and Developmentally Disabled Persons.

Four major areas will be addressed in the revised standards. Those areas are: administrative services, active treatment services, physical environment, and safety and sanitation.

The Department believes the proposed revisions to the ICF/MR standards will ensure that clients are provided quality care, and that facilities will be relieved of the duplicative requirements contained in the current regulations, thus reducing their operating costs. As the focus shifts from the institution to the client, these proposed changes should put State surveyors in a better position to determine whether active treatment is actually occurring for each client. This determination is important to ensure that those who work with clients deliver accountable, habilitative services which result in the clients' growth and development. Ensuring active treatment improves the chances of integration into the community, resulting in more effective expenditure of Medicaid dollars in the ICF/MR setting.

3. Services for Adults

The Department is committed to the promotion of independence and productivity for all developmentally disabled citizens. One particularly problematic area is that of work and vocational services. The typical experience for mentally retarded people has frequently been limited to day activity centers, which focus on the acquisition of daily living skills. The other primary option has been sheltered employment, segregated facilities providing some sort of work activity with compensation. A relatively few individuals have achieved mainstreamed employment.

On-site training or follow-along support are sometimes required to increase the likelihood of successful job placement.

Medicaid funding is not available to fill this service gap since it is a reimbursement program for medical and health needs. Its application to the provision of vocational services is therefore limited.

Vocational preparation and training are provided by some public schools. Higher functioning individuals may be eligible for Vocational Rehabilitation services. Those persons who do not become clients of Vocational Rehabilitation are usually served in day activity programs which are generally non-vocational and administered by social services or developmental disabilities agencies.

The Federal government is working to address these needs through a variety of projects and initiatives. The Administration on Developmental Disabilities has mounted a major employment initiative to expand employment opportunities for persons with disabilities in the private sector. Through extensive efforts with private employers, trade associations, and State and local service providers, 25,000 persons with developmental disabilities achieved competitive jobs in 1984. These jobs were in a variety of industries including restaurants, hospitals, electronics firms, and hotels.

A recent survey of placement facilities indicates that there is an 85 percent retention rate for those holding full-time jobs. In 1985 the Administration on Developmental Disabilities set a goal of 50,000 new jobs for persons with developmental disabilities.

The Social Security Administration is implementing a transitional employment demonstration. Eight nonprofit organizations have been awarded grants to provide transitional employment training to about 400 mentally retarded SSI recipients.

The Department of Education and the Department of Health and Human Services will be funding supported work models in five or six States during FY 1985. The projects will provide on-the-job training and continued help at the workplace. This initiative is designed to stimulate cooperation between vocational rehabilitation agencies, State offices of Mental Retardation/Developmental Disabilities and other State agencies to promote mainstreamed employment opportunities for mentally retarded and other developmentally disabled people.

The Department of Health and Human Services, Office of Planning and Evaluation, is interested in examining Federal, State and

local policies and practices which support or impede the coordinated delivery of a broad spectrum of adult services including vocational and pre-vocational assistance. The purposes of this work are two-fold:

- o to identify successful State practices which capitalize on the flexibility of the current reimbursement system and to share these practices with other States; and
- o to identify the legislative, regulatory and administrative barriers at all levels of government which impede coordinated service delivery as well as approaches to overcoming these barriers.

The Department will encourage the guidance and participation of other appropriate Federal agencies in this study.

4. Interagency Coordination

The Developmental Disabilities Act of 1984 calls for the establishment of an interagency committee to coordinate and plan activities conducted by Federal departments and agencies for persons with developmental disabilities. This committee is co-chaired by designees of the Secretaries of this Department and the Department of Education: the Commissioner of the Administration on Developmental Disabilities and the Assistant Secretary of Special Education and Rehabilitative Services, respectively. Other agency representation includes: Housing and Urban Development, Labor, Justice and the National Council on the Handicapped. Relevant offices in the Departments of Health and Human Services and Education are represented as well. The committee met for the first time on September 26, 1985. One of the first agenda items is the examination of issues concerning adult services and program coordination outlined above. An interagency approach to these concerns is both fitting and necessary.

In order to ensure intra-agency coordination, the Department is also committed to improving coordination among its own offices and agencies in addressing the concerns of mentally retarded and other developmentally disabled persons.

CONCLUSION

This report identifies four goals and related policies for improving services for the mentally retarded and other developmentally disabled persons served under Title XIX of the Social Security Act. Some of the recommendations in this report can be accomplished administratively and others require congressional action. We are prepared to work with the Congress to implement these proposals. We will assess the impact of these changes and actions and make or propose other changes, as appropriate.

In addition, the Department will continue to examine services for mentally retarded and other developmentally disabled people. The needs of this population are varied and range from medical, to residential, to habilitation and training. Generally, more severely disabled people require more intensive services. Further exploration of types of services and mechanisms for organizing and delivering them will be undertaken.

The following is an update on BCFA's continuing enforcement efforts with regard to nine public ICFs/MR identified by the Secretary in July 1984 in hearings before Senator Weicker.

Fairview Training Center - (Oregon)

ECFA approved a plan of correction calling for a reduction in the census of the facility, physical plant improvement, the hiring of over 400 direct care and other staff, and the provision of active treatment services to clients. The facility is reporting to HCFA on a monthly basis and corrections are proceeding on schedule.

Enid and Paul's Valley State Schools - (Oklahoma)

ECFA approved plans for these two sister facilities that included extensive physical plant renovations, increased staffing, and improved active treatment services. The Dallas Regional Office revisits the facility quarterly. Significant improvements have been made.

Wheat Ridge Development Center - (Colorado)

The State Legislature appropriated over \$2 million to fund necessary additions of direct care and professional staffs. The facility is reevaluating its clients' needs for services and has been improving its programs.

Staten Island Developmental Center - (New York)

Despite the acceptance of a plan of correction for this facility, HCFA found in a resurvey in 1985 most of the deficiencies remained and others were added. The facility was notified by HCFA that its participation in Medicaid was being terminated. Before the termination became final, the State moved half of the clients (over 200) to other settings, made significant sanitation and environmental improvements and hired needed staff. The termination was rescinded.

Letchworth Developmental Center (New York)

Federal surveyors also found serious repeat deficiencies at Letchworth a year after the first survey conducted revealed major problems in health care and active treatment services. The facility was notified that its participation in Medicaid was being terminated. The termination is pending an appeal by the facility.

Newark and J. K. Adams Developmental Centers (New York)

HCFA accepted plans of correction for these two facilities. Problems included a lack of active treatment services and physical plan deficiencies. Federal surveyors will resurvey these facilities in 1985.

Mansfield State School (Connecticut)

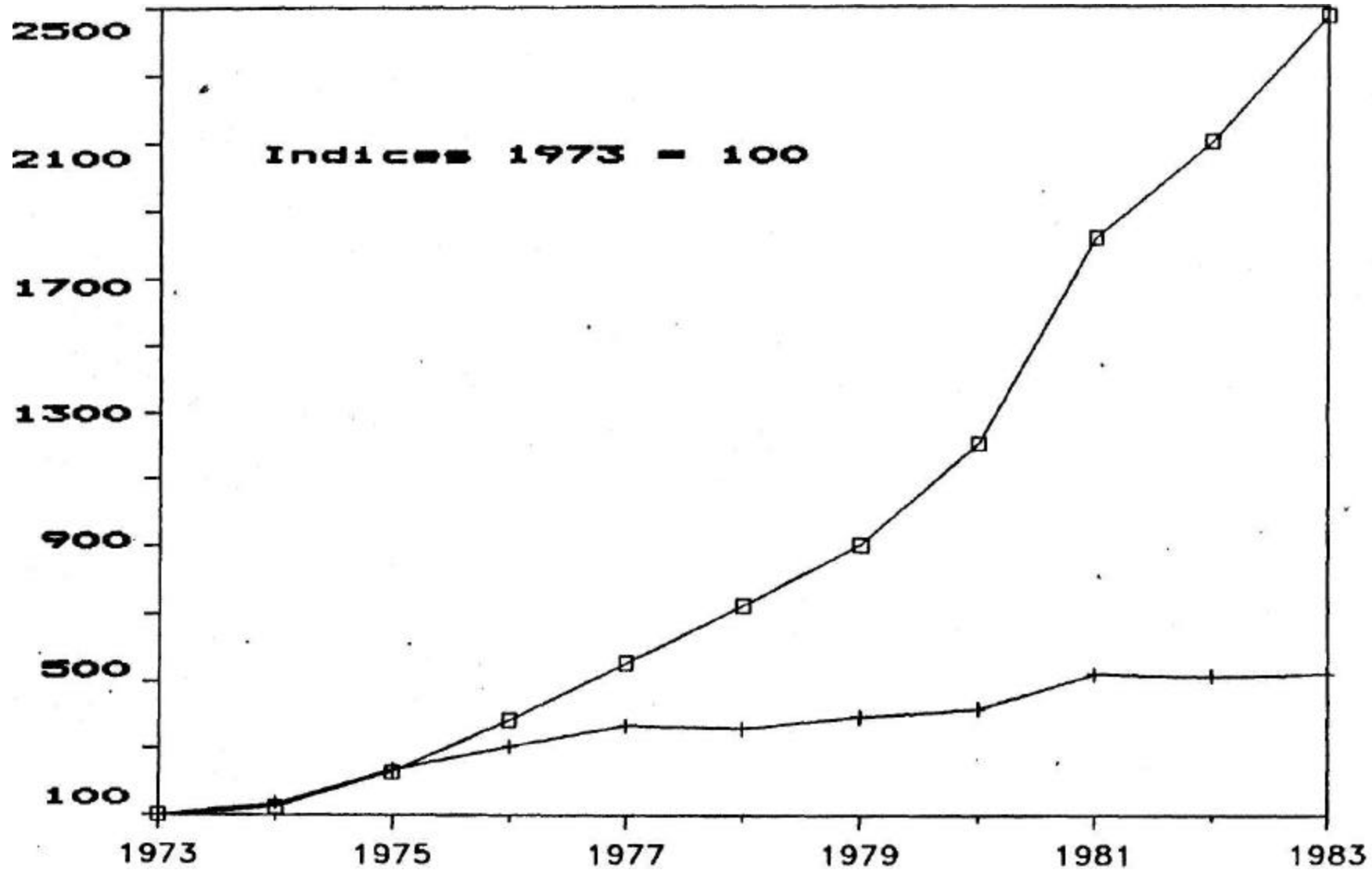
HCFA accepted a plan of correction calling for improved active treatment programs, including behavior modification programs. The facility is undergoing administrative and leadership changes. The regional office will complete a follow-up survey in 1985.

In each of these cases, the forms of plans of correction are directed toward improvement in the facilities' ability to deliver services directly to clients that lead to greater personal client independence, productivity and potential for integration into the broader community. Each of these facilities continues to place additional clients in community settings, which has the added benefit of enabling the facility to use its existing resources for the fewer remaining clients.

CHART

ICFs/MR, United States, FY 1973 - 83

Medicaid Expenditures & Recipients



a Expenditures + Recipients

SOURCE: Based on Information provided by the Health Care Financing Administration.

TABLE A

**ICFs/MR in the United
Number & Size of Institution and
Beneficiaries Served**

Number of institutions, by Size

Year	1977	1982
Small institutions (under 15 beds)	188	1,202
Large institutions (15 beds & over)	389	652

Beneficiaries

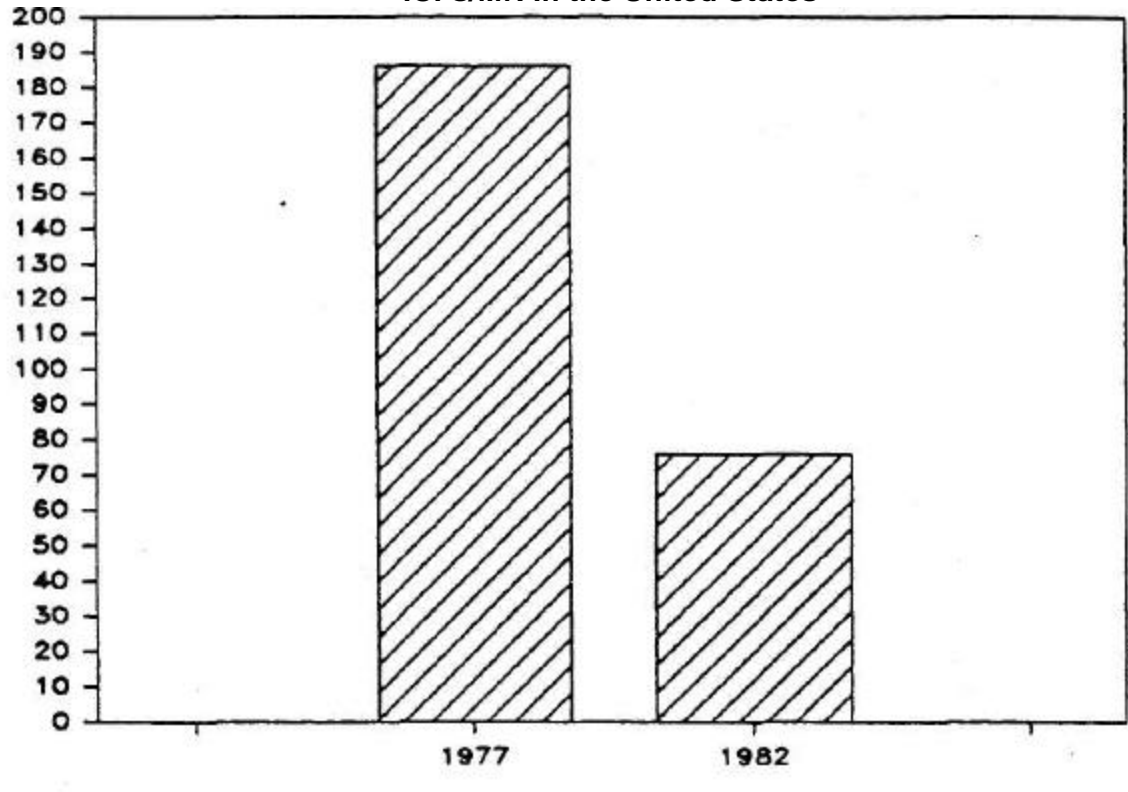
Year	1977	1982
Small institutions (under 15 beds)	1,710	9,714
Large institutions . . . (15 beds & over)	105,207	130,970

SOURCE: Compiled from the 1977 and 1982 National Census of Rehabilitation Facilities conducted by the Center for Residential and Community Services, University of Minnesota.

CHART II

Number of Beds per Facility

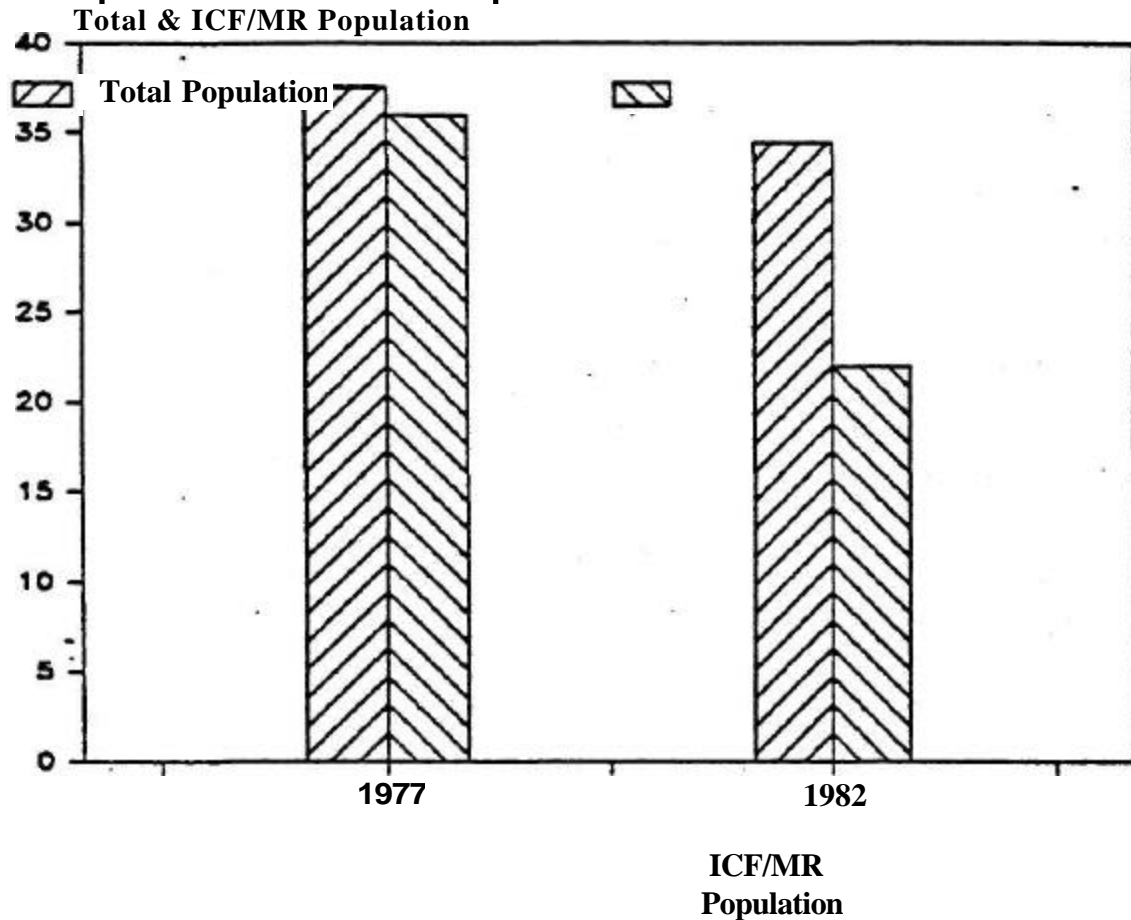
ICFs/MR In the United States



SOURCE: Based on the 1977 and 1982 National Census of Residential Facilities conducted by the Center for Residential and Community Services, University of Minnesota.

CHART III

Proportion of Population Under 22 Years



SOURCE: Based on the 1977 and 1982 National Census of Residential Facilities conducted by the Center for Residential and Community Services, University of Minnesota.



UNITED STATES DEPARTMENT OF EDUCATION
OFFICE OF THE ASSISTANT SECRETARY FOR
SPECIAL EDUCATION AND REHABILITATIVE SERVICES

DEC 6 1985

Mr. Arnold Tompkins Deputy
Assistant Secretary
for Social Services Policy Department
of Health and Human Services Room 410E
HHH Washington, D.C. 20201

Dear Mr. Tompkins:

I am pleased to acknowledge Secretary Heckler's September 30, 1985 request for comments on the Report to the Congress on Policies for Improving Services for Mentally Retarded and Developmentally Disabled Persons Served under Title XIX of the Social Security Act. We have reviewed the report and recommend that it be forwarded to Congress.

In response to the provisions of the Developmental Disabilities Act of 1984, I would like to address the recommendations made in the report and note the impact of these recommendations on the Department of Education programs.

The Department of Health and Human Services (DHHS) goals of increasing incentives for community living, meeting the service needs of adults, and improving interagency coordination and cooperation in providing services complement initiatives of the Office of Special Education and Rehabilitative Services (OSERS) and goals of this Department.

The DHHS goal of increasing incentives for community living is a counterpart to the OSERS goals of providing services to severely disabled persons in the least restrictive environment and supported employment. The Office of Special Education and Rehabilitative Services believes like DHHS that existing funding mechanisms to meet the needs of the developmentally disabled population should be examined with an emphasis on the development of new mechanisms to reduce barriers and disincentives to employment and community living.

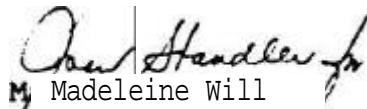
The goal of meeting the needs of adults complements the Office of Special Education and Rehabilitative Services recognition of the need for an examination of adult services. A "National Forum of Disability Policy" will be convened by the Office of Special Education and Rehabilitative Services. During the forum, major groups from both the public and private sectors will review major policy options, including disincentives, in meeting the needs of developmentally disabled adults.

Page 2 - Mr. Arnold Tompkins

As noted in this report, an interagency committee to coordinate and plan activities conducted by Federal departments and agencies for persons with developmental disabilities is co-chaired by designees of the Secretaries of this Department and the Department of Health and Human Services: the Assistant Secretary of Special Education and Rehabilitative Services and the Commissioner of the Administration on Developmental Disabilities, respectively. We believe that this committee is a good mechanism to, at the Federal level, begin to change what has historically been a fragmented system of services which has impeded achievement of independence and employment for the mentally retarded and developmentally disabled population.

In summary, the Department of Education supports the goals set forth in the report. We look forward to working with you so that we may move forward in reaching these goals.

Sincerely,


M Madeleine Will
X Assistant



National Council on the Handicapped

800 Independence Avenue. S.W.
Suite 814 Washington, DC 20591

202-453-3846

**An Independent
Federal Agency**

December 23, 1985

Honorable Otis Bowen
Secretary
Department of Health and Human Services
Room 615F
200 Independence Avenue, S.W.
Washington, D.C. 20201

Dear Secretary Bowen:

The National Council on the Handicapped is pleased to have had the opportunity to review and participate in the development of the Report to Congress entitled, "Policies for Improving Services for Mentally Retarded and Developmentally Disabled Persons Served Under Title XIX of the Social Security Act". We commend the Department of Health and Human Services for its leadership in the development of this important document. We find the report thorough and comprehensive in its coverage of services needed and provided as part of the Medicaid ICFMR program.

The Council agrees in general with all of the issues and recommendations addressed under the four principal areas outlined in the report. However, the Council suggests that the issues covered under the area on "improved standards" be expanded to address the important issues of: a. adequate preventative and disciplinary measures to prevent residents against abuse in ICFMRs and other types of facilities; and b. appropriate standards and criteria for personnel working in ICFMRs.

The Council believes that the expertise required in the ICFMR of the mid-1980's and 1990's is vastly different from that required when the existing pertinent regulations were published in January 1974. The dependence oriented medical bias which has been a part of the ICFMR program since its inception must be replaced with an attitude and an environment that facilitates independence and productivity by people with disabilities. People working in ICFMRs- should be appropriately trained and their work should be monitored and supervised to insure that high quality performance standards are met. Finally, the Council feels that appropriate rehabilitation and training should be provided for all mentally retarded and developmentally disabled persons and recommends that the Health Care Financing Administration study and suggest means by which people who are assisted under the Medicaid ICFMR program can receive such services.

In the process of reviewing legislation and programs affecting the lives of people with disabilities, the Council has discovered a wide array of disincentives and barriers to productivity and independence for people with all disabilities, including those who are mentally retarded and developmentally disabled. We have prioritized Federal programs serving people with disabilities according to the amount of money being spent on those programs and the number of people served by them, and we have concluded that a disproportionate amount of the public resources which are targeted to assist the disabled population is used to sponsor dependence oriented programs rather than those which encourage independence.

The Council stands ready to work together with the Department of Health and Human Services, other Executive Branch agencies, and the Congress to change the emphasis of our present programs and policies so that they encourage and reward personal responsibility and self-sufficiency on the part of people with disabilities.

Sincerely,

A handwritten signature in cursive script, reading "Sandra S. Parrino", followed by a vertical line.

Sandra S. Parrino
Chairperson